Facts About...

HIV/AIDS Epidemiology Program
206-296-4645

HIV Reporting in Washington State

At its July 1999 meeting the State Board of Health voted unanimously to implement HIV case reporting in Washington State. Reporting started September 1, 1999 and applies to both adult/adolescent and pediatric HIV cases. The final HIV reporting plan as adopted by the Board of Health is unique among all the reportable diseases in Washington in that names are used only in the initial case report and then converted to a non-name code within three months. Washington's system is also unique among the 33 states which require named HIV reporting. This fact sheet asks and answers the most common questions about how the HIV reporting system works in Washington State.

Q. What does it mean for HIV to be reportable? HIV is now one of more than 50 diseases of public health importance in Washington State for which health care providers must report cases to local health departments. Other diseases that are reportable include tuberculosis, measles, whooping cough, rabies, food-borne illnesses, and many sexually transmitted diseases.

Disease case reports are maintained by health departments with even more security than is typically true of confidential medical records. Information gained from disease reporting is used to plan care and disease control programs and, depending on the specific disease, to prevent further spread and assure treatment of individual cases of disease.

Q. When did AIDS and HIV reporting begin? Reporting of cases of AIDS began country-wide in 1984, soon after AIDS was first described. In 1987, symptomatic HIV infection became reportable by name in Washington State in recognition of the wider spectrum of serious illness caused by HIV. In July 1999, the State Board of Health passed a rule making asymptomatic HIV infection reportable beginning September 1, 1999.

Q. Why was HIV infection reporting adopted at this time? About 8,500 cases of AIDS or symptomatic HIV have been reported in Washington State. Of these, about 3,500 are living. Another 6,000 to 8,000 HIV-infected persons with HIV are estimated to reside in the state. People with HIV infection are now staying healthier, leading more productive lives, and staying free of AIDS longer with the help of powerful new drug combinations. In fact, the number of new cases of AIDS in this state has dropped from a high of 650 in 1993 to about 300 in 1997.

At the same time, it is thought that the number of HIV infections has gradually increased since 1993, however, without HIV reporting this cannot be measure directly. This means that the tracking of AIDS cases is no longer a reliable way to understand the epidemic. Expanding to include reporting of all cases of HIV infection was necessary to better understand the current dynamics of HIV transmission and to better define the scope of the epidemic and the services necessary to address it. The majority of states now require HIV reporting.

Q. Are the names of persons with HIV and AIDS reported? I've heard about coding of names—what is this about? As for all other reportable diseases in Washington State, HIV and AIDS are reported by name and other identifiers. However, for cases of asymptomatic HIV infection, the name of the person will be converted to a non-name code within 90 days after the receipt of a completed case report. Case reports on AIDS and symptomatic HIV will continue to be retained using names, as has been done since 1984.

For HIV cases, having the name initially reported allows public health staff to complete case reports and accurately create the unique identifier (non-name) code. In the few states that have pure unique identifier reporting (e.g., Maryland and Illinois) the provider or

laboratory must formulate the code; this creates a burden on providers and labs, and leads to inaccurate or incomplete codes that hinder the ability to eliminate duplicate cases or do other quality assurance activities.

Q. Why are codes being used for HIV cases? Nearly two years of intense public debate preceded the State Board of Health's decision to adopt this system of named reporting with subsequent conversion to a non-name identifier code. While over 8,000 AIDS and symptomatic HIV cases have been reported by name without a breach of confidentiality in Washington State, there was concern on the part of many members of the AIDS advocacy community about the confidentially of HIV case reports. Some of the concerns were: What if someday some government agency demanded the registry of HIV cases from the state health department? What if named HIV reporting stopped some people from having an HIV test or seeking care? What if someone breaks into the computer system or health department offices to obtain the names?

The State Board of Health and state and local health departments recognized the concerns of the community and sought to develop a system that would provide increased protections and not deter HIV testing by those at risk of infection. What was finally adopted was an innovative system of HIV reporting that combines features of both standard named reporting and unique identifier systems used in a few states (see accompanying table). It is felt that this system will provide high quality epidemiological data and allow the disease control functions of public health to take place while alleviating concerns about having a named statewide HIV registry maintained in perpetuity. The system as implemented was supported by major community advocacy groups in the state including the Governor's Advisory Council on HIV/AIDS, Northwest AIDS Foundation, and the People of Color Against AIDS Network.

Q. How does this new system of HIV reporting work in Washington State? Health care providers and laboratories report cases of HIV and AIDS by name to the local health department. For cases of asymptomatic HIV infection, patient names are encoded by the local health department within 90 days after receipt of a complete case report. For smaller local health jurisdictions without the capacity to gather case reports, state health department staff may act as an agent of the local department for the purpose of collecting and completing case reports. However, patient names will be left at the local health department and not retained by state staff. Within 90 days, patient names are encoded then destroyed from both hard copy and computer reports.

Only the coded identifier is sent to the state Department of Health or on to the CDC. Thus, the state and federal government never have a list of names of persons with asymptomatic HIV and local health departments have the names for only 90 days. Laboratory reports are used to supplement provider-based reporting and have been found to greatly improve the completeness of case reporting (see next question).

Q: What if a health care provider forgets to report a case? By law, HIV and AIDS cases are to be reported within 7 days of diagnosis. However, often times providers do not report on time or assume that another care provider has reported the case. To assure complete and accurate epidemiological data, supplementary laboratory reporting of results diagnostic of HIV and AIDS (like many other diseases) has proven essential. Nearly all HIV-infected persons receiving health care from a provider have periodic laboratory tests to assess the effectiveness of treatment in reducing the amount of HIV in their blood ('viral load' tests) and to determine how well their immune system is functioning (CD4 tests).

Results of these tests which indicate HIV infection or AIDS must be reported by laboratories to public health. These lab reports are checked against already-reported cases using the non-name code and unreported cases prompt a call to the health care provider who ordered the test to verify the case and complete a report. The health care provider is then educated about the rule and provided with ongoing assistance in achieving communicable disease reporting compliance in the future.

Q. What is the non-name identifier code like? Unique identifier codes work by including enough information about an individual to be unique, that is to be able to distinguish one case report from another. The code, however, cannot be translated back into a name. Information in the coded identifier in Washington includes gender, patient birth date, alpha-numeric code elements generated from the first and last names; and the last four digits of the social security number. This code is non-identifying yet contains enough information unique to each individual that coded cases in the registry can be matched accurately to incoming lab reports, subsequent duplicate case reports, or death records.

Q: Can people still get anonymous testing for HIV? Yes. The availability of anonymous HIV testing is considered vital and public health officials across the state are required by the new rule to make anonymous testing reasonably available. Anonymous testing is available through all local health jurisdictions, other community organizations in some jurisdictions (e.g., Planned Parenthood clinics), and through home testing kits available in many pharmacies. Sites offering anonymous HIV testing can be located by calling the HIV/STD Hotline sponsored by Public Health—Seattle & King County at 206.205-7837 (services are available in Spanish) or the Washington State HIV/AIDS Hotline at 1-800-272-2437. Both hotlines operate from Monday through Friday, 8 am to 5 pm.

Q: Are anonymous HIV test results reportable? No. Positive HIV results obtained through anonymous testing are not reportable. However, when HIV+ patients are seen for health care the case must be reported by the provider. Reporting is done only after the provider has seen the patient and had a chance to answer any questions the patient may have about the 'hows and whys' of reporting.

Q. Are there other circumstances when HIV is not reportable? Yes. In writing the HIV reporting rule, the Board of Health exempted providers conducting clinical HIV research from reporting if the research has institutional (human subjects) review board approval and if the project has a system in place to remind the subjects' main health care providers of their HIV/AIDS reporting obligations.

Q. How is the privacy of persons reported with HIV protected? Health care providers and public health officials remain bound by the same stringent confidentiality laws which have been applicable to AIDS and other sexually transmitted diseases (RCW 70.24.105,WAC 246-100-016). Records relating to HIV & AIDS, like those of sexually transmitted diseases, drug abuse, and mental illness have exceptionally protected status. Violation of these confidentiality laws is a misdemeanor and is subject to civil liability action for reckless or intentional disclosure up to a penalty of $10,000 or actual damages, whichever is greater.

For decades, health providers have reported the names of people infected with other communicable diseases, such as syphilis, gonorrhea and tuberculosis and maintained the highest level of confidentiality. Extra measures have been built into the HIV/AIDS reporting system in Washington State to further safeguard persons from potential discrimination and to reassure those concerned about named reporting through the feature of converting names to codes soon after reporting.

Public health workers are trained in protecting confidentiality and are committed to safeguarding the privacy of persons infected with HIV, as they always have been with AIDS. Extensive measures are taken to assure the confidentiality and security of case reports and computers used to store data, even when these records do not contain patient names.

Q. What is the connection between HIV/AIDS partner notification and HIV reporting? Washington State law requires health care providers to offer partner notification assistance to persons diagnosed with HIV infection (RCW 70.24.320(2) and RCW 70.24.022) and the state's administrative code establishes the rules for providing such assistance (WAC 246-100-072). The new HIV/AIDS case report form now in use in Washington State includes a check box for providers to request local health department assistance in discussing or conducting partner notification for HIV cases diagnosed after 9/1/99. The provider may also indicate that he or she is assuming the responsibility for discussing partner notification with the patient and offering a partner notification interview.

If the reporting provider requests health department assistance or if neither box is checked, local health department staff trained in STD/HIV partner notification services will contact the provider to discuss partner notification issues; patients will be contacted by public health staff only after discussions with the primary provider and with consent of the patient. Notification of sex or needle-sharing partners is entirely voluntary and depends on the cooperation of the person diagnosed with HIV.

Q. How will public health officials know if reporting of HIV cases is giving useful results? The Department anticipates that 4,000 to 5,000 HIV case reports will be submitted in the first two years after the start of HIV reporting. Most of these cases will be persons previously diagnosed with HIV, but as many as 750 per year statewide will be new HIV infections. The risk information obtained on these newly-diagnosed persons will provide public health officials and the community with a much clearer understanding of the current epidemiology of ongoing HIV transmission in Washington State. Information on the combination of previously-diagnosed and newly-diagnosed cases will give a much more accurate estimate of the number of HIV infections in Washington and how they are distributed throughout the state. Comparisons to older data on AIDS cases will provide information about epidemiological trends in HIV transmission.

As part of the new HIV reporting rule, the Board of Health mandated that the State Health Officer report on an evaluation of the reporting system after 12 months of operation — to assess its ability to meet federal performance standards for HIV surveillance in terms of completeness, timeliness, and accuracy; the costs to local and state public health operations; the impact on disease control; and any effects on HIV test- and care-seeking behavior of high risk groups.

Q. How is the information collected through HIV and AIDS reporting disseminated and used? State and local health departments prepare a variety of regular reports, newsletters, and slide series containing compiled AIDS case report data. These will be updated in late 1999 and into 2000 to contain HIV case report data. Reports are sent to established mailing lists and some (such as this report) are available in the Seattle and King County library systems and in certain schools and colleges. Many of these reports are now posted in public health web sites such as www.metrokc.gov/health/apu/. Case data from Washington State are also sent monthly to the federal Centers for Disease Control and Prevention and become part of the national statistics on HIV and AIDS.

Information from case reporting is used to:

❑ *Direct HIV prevention programs to populations and geographic locations most affected;*

❑ *Determine the level of need and plan AIDS care services;*

❑ *Understand the changing epidemiology and future impact of the epidemic;*

❑ *Evaluate the effectiveness of HIV prevention programs;*

❑ *Allocate funds and other resources for HIV prevention and treatment equitably;*

❑ *Apply for federal funds based on the number of HIV/AIDS cases reported;*

❑ *Educate individuals on routes of HIV transmission and their risk profile;*

❑ *Educate legislators and other policy makers on the magnitude of the epidemic and the need for continued funding of prevention and care services.*

Q. Where can I get more information about HIV reporting? You can contact your local health department or regional AIDSNet director. In Seattle-King County, call Drs. Susan Barkan or Sharon Hopkins at (206)296-4645. They can be reached by email at:

susan.barkan@metrokc.gov, or
sharon.hopkins@metrokc.gov.

At the Washington Department of Health, contact Dr. Christopher Spitters at (360)236-3412 or Jack Jourden at (360)236-3466. Copies of the WA Administrative Code pertaining to HIV/AIDS reporting and confidentiality of reported data are available upon request.